Review of advance care planning for people with cancer

Literature review
2020
Acknowledgements

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Introduction

This rapid literature review identifies and describes Australian academic literature relating to advance care planning for people with cancer. The report focuses on key themes from the literature, including evidence of barriers and facilitators to advance care planning for people with cancer. The report identifies limitations in the evidence and the need for Australian research, policy and programs to support quality advance care planning in cancer care.

Background

In 2018, it was estimated that 138,300 new cases of cancer will be diagnosed in Australia, an average of about 380 people every day. (1) The risk of being diagnosed with any cancer before the age of 85 will be 1 in 2 for males and females. (1) Cancer has been identified as a leading cause of death in Australia with almost 50,000 deaths estimated for 2019. (2) The year following diagnosis and the last year of life are the most resource intensive stages of cancer care. (3) During this time people often face complex and difficult decisions related to end-of-life care planning (4, 5). It is known that older persons with cancer are less likely to receive information about their illness and fully understand the implications of available treatment options in comparison to their younger counterparts (6) which can impact on their ability to have meaningful participation in care related discussions and make informed treatment decisions. In addition to this, evidence shows that 28-48% of patients with advanced cancer experience delirium on admission to hospital (7) and that 90% of these patients experience delirium in the days before death (7, 8) which will subsequently impact on their decision-making capacity.

Advance care planning (ACP) is the process of planning for future health and personal care whereby a person’s values, beliefs and preferences are made known so they can guide clinical decision-making at a future time when that person cannot make or communicate their treatment decisions. (9) The ultimate goal of ACP is to align the care the person actually receives with their preferences for care. Research shows that patients who discuss their preferences for end-of-life care are more likely to choose less aggressive treatment (10) and to receive care which is consistent with their preferences. (11) An Australian study found that overall health care costs were significantly higher among those who died from cancer than any other causes, with 40% of costs expended in the last month of life. (12) In general medical settings, ACP is associated with a number of improved outcomes at end of life, including reduced hospitalization, increased likelihood that the person will
die in their preferred setting, and reduced stress, anxiety and depression in surviving loved ones. (13-17) In Australia, benefits of ACP documentation in an oncology population have been recognised across many policy documents including statewide cancer action plans, National Optimal Care Pathways for oncology and the National Palliative Care Strategy 2018. These policies aim to increase the uptake of advance care plans in order to deliver person-centered care and quality of life for those with a cancer diagnosis. (18-25) Yet despite increasing recognition of the importance of ACP in people with cancer in practice guidelines and recent literature, delivering ACP for people with cancer is complex and the uptake remains low in Australia and internationally. (26-30) A 2017 Australian National Advance Care Directive Prevalence Study reported that only 27% of people with a cancer diagnosis had documented their ACP preferences in an advance care directive. (31) Studies have found that the values and needs expressed by cancer patients and their response to ACP differs from other patient populations. (32) There is evidence that patients with advanced cancer vary in their willingness to participate in ACP discussions. (33) Many studies have reported on the patient, health care provider and system barriers (34, 35) which impact on the uptake of ACP in the oncology population including patient anxiety (36, 37), lack of patient comprehension and awareness of ACP (35, 38), insufficient physician training in end-of-life communication (36, 37), lack of time for clinicians to have ACP conversations (39), challenges in determining the appropriate time and setting for initiation (38) and overly prescriptive policies which encouraged ‘tick box’ approaches to ACP. (40) In addition to this, the unpredictable disease trajectory, equivocal treatment options and poor understanding of prognosis can be a unique barrier to this population (41, 42). One of the reported difficulties of implementing an ACP intervention on a larger scale is determining which member(s) of the health care team will be responsible for completing ACP. Bestvina et al. (43) reviewed 26 studies assessing the prospective interventions that address ACP in the oncology setting and found that many studies relied on a research assistant who would not typically be available in a standard healthcare environment. Other studies used either a nurse, advanced practitioner, palliative care physician or oncologist or a mix of palliative care physicians, nurses, social workers, advance care providers to conduct the ACP session. (43) These results point to a lack of clarity of whose responsibility it is to initiate ACP conversations in people with cancer. Overall, it is not entirely clear as to why ACP has not been integrated into routine care for people with cancer however many systematic reviews have acknowledged that ACP is a complex and dynamic process which requires many personal, emotional, social and legislative factors to align. (35, 44-46) This rapid review aims to examine Australian primary studies reporting on advance care planning in
people with cancer to further understand the efficacy of advance care planning in this population including any existing barriers and facilitators to uptake. We aim to inform practice guidelines and future models of advance care planning in the oncology setting for the Australian context.

Methods

A rapid review of published peer reviewed literature relating to advance care planning and cancer was undertaken. The articles included in the review were published between 2015 and 2019 to reflect recent research of advance care planning in the oncology population. Searches were conducted using Ovid MEDLINE, Embase, PsycINFO and Ovid Emcare. The search strategy used a range of terms to identify relevant publications including: advance care planning; advance care plan; advance care directive; home support or aged care assessment; cancer; neoplasm; carcinoma; tumor; oncology; malignancy; metastatic; leukemia; adenoma; adenocarcinoma; lymphoma; melanoma; sarcomal blastoma; mesenchymoma; mesothelioma; thymoma; hepatoma; hepatoblastoma.

All article abstracts and publication executive summaries were reviewed for relevance to advance care planning and cancer. For those articles and publications that were relevant, the full manuscript was reviewed. Studies were included if the research was published between January 1 2015 and 30 June 2019 and completed in adult populations. Only Australian studies using qualitative and quantitative research methods were eligible for inclusion. Articles published before January 1 2015 were excluded to ensure relevance of the findings to the current landscape of advance care planning. Articles published in languages other than English were also excluded.

Results

The search strategy produced 649 references. After deletion of duplicates and eligibility assessment, 11 articles were included for full review. Many studies used qualitative or mixed research methods. Most studies (n=18) were published in 2018 and 2019, suggesting increasing research interest in this topic.

Ten studies included people with cancer participants, six studies included their support person and 1 study had oncologist and palliative care physician participants. Of the consumer research conducted in Australia, oncology patients were from metropolitan health services. 54% (n=6) of studies
featured fewer than 100 participants and 73% (n=8) were based in one or two health services. From the 10 studies that included people with cancer, 50% (n=5) focused on those with metastatic or incurable disease. The characteristics of each study are provided in Table 1.

**Synthesis of Findings**

Thematic synthesis was undertaken to identify recurring concepts from multiple studies and develop a thematic framework to convey the main themes in the relevant Australian literature. Five main themes were identified: prevalence of ACP in people with cancer, people with cancer and their support people’s views of ACP, concordance between people with cancer and their support person’s views, oncology healthcare professional views of ACP, and barriers and facilitators of ACP. A summary of the classification of included articles according to theme is provided in Table 1.

**Prevalence of ACP in people with cancer**

Six of the 11 studies (47-52) examined prevalence of advance care planning in the oncology population. The definition of advance care planning varied amongst all studies and included both statutory, non-statutory and medical order documents as well as documented evidence of verbal communication of a person’s values and preferences.

Overall, very few people with cancer had documented their values and preferences for medical treatment, with studies showing documentation was completed in approximately 6-15% of participants. (47-50, 52) Hamid et al., investigated both the prevalence and timing of completion of ACP and showed that 15% of patients had a written ACP which was accessible to the treating team and it was completed on average of 3.7 months prior to death. (47) Similarly, in a study completed by Waller et al., only 6.3% of medical oncology outpatients had recorded their care preferences despite stating they wanted decisions made from a care plan they had written if they lost capacity. (50)

Despite low prevalence of written documentation of advance care planning in people with cancer, three studies all completed by Waller et al., also investigated the conversations that those with cancer had with the people around them. Overall, 36-63% of them had discussed their end-of-life preferences for care with their support people (49, 51, 52) however, only 7.4-11% had discussed them with their doctor. (49, 52)

**People with cancer and their support people’s views of advance care planning**

Overall, people with cancer and their support people recognised the importance of advance care
planning especially in relation to end-of-life care. Patients discussed the benefits it had on their emotional wellbeing by making them feel empowered and respected, giving them peace of mind, making them feel secure and calm that their wishes were known, (53-55) as well as helping to remove difficult decisions from family (54-56).

Carers expressed similar views stating “I don’t know if [advance care planning] made a difference to his care. I don’t know about that. I know it made it easier for the rest of us.” (53) They also described ACP as “lift[ing] a huge burden from caregivers.”

When people with cancer were asked about who they would want to make their medical treatment decisions if they were not able to, most people had a preference for their doctor in consultation with their family or by a documented plan they had completed themselves. (49) Very few patients wanted their doctor to make end-of-life care decisions without consultation. (49)

Approximately half of the people with cancer in a study by Waller et al., reported that they would want the first discussion of end-of-life care preferences to occur when their disease became incurable. (49) This requires patients to have an accurate perception of the likelihood of cure for their disease as well as a discussion about prognosis with their oncologist. The complexity of relying on prognosis to initiate ACP conversations was highlighted by Hamid et al. (47) They found that a quantitative description of prognosis was only present in 14% of an oncology patient’s internal correspondence and 7% of their external correspondence and that it was first documented 2.2-3.5 months before death. (47) This reflects the lack of communication between oncologists and other healthcare professionals about prognosis which could have implications on ACP and delivering patient-centered care. Patients have also recognised that they require more information and discussion about prognosis from their oncologist. (52) It is difficult for patients to engage in the development of an appropriate or comprehensive ACP if they do not have a good understanding of their own prognosis.

In all studies, people with cancer valued completing advance care planning and discussing their end-of-life care wishes with their with their support people (49, 52-54, 56). The positive views held by patients regarding advance care planning however, did not consistently translate into action, with prevalence of documentation being low (47-52). This indicates that people with cancer are relying on conversations with their support people to guide medical treatment decisions.

Concordance between people with cancer and their support person’s views

Many of these studies have shown that relying on the views of the support person may not always
result in decisions that are in accordance with a patient’s views. (48, 50, 51) Agreement between people with cancer and their support people were minimal when it came to the type of end-of-life care people with cancer would prefer i.e. life prolonging or symptom management (50). It was shown that patients’ decisions in relation to end-of-life care were strongly influenced by pain and level of consciousness however the support person’s choices were only influenced by pain. (51) A few studies have demonstrated that there is a trend for those who have discussed their wishes with family to report higher agreement than those who had not. (48, 51)

**Oncology healthcare professional views of ACP**

Only one of the 11 studies explored oncology healthcare professionals views of advance care planning. It explored oncologists and palliative care physicians’ perspectives of autonomy and highlighted that ethical assumptions regarding patient autonomy embedded in academic literature and policy documents relating to ACP are disconnected from the realities of clinical care. (57) Medical norms and professional boundaries surrounding what is considered to be a ‘good death’ have a greater influence on care than patient preferences. (57) One oncologist stated “we tend to respect autonomy, but the other side of the coin is somebody says, ‘I want you to resuscitate me no matter what my underlying condition is,’ then I won’t respect that autonomy”. (57) Whilst patients are encouraged to express their preferences for care, it highlights that patient autonomy in healthcare is bounded. There was also some consensus that oncology was different to other clinical areas when it came to advance care planning “I think in oncology, the scenario’s a little bit different, because usually I’ve known the patients for a long time throughout their illness.”(57)

Despite this, most oncologists were aware of the benefits of ACP beyond just supporting patient autonomy, namely, reducing or resolving conflict within families or healthcare teams, reducing stress on family members and easing the burden of decision-making for healthcare providers. (57) “The value of having things in place is that it reduces stress on the family. And families like to know that they’re doing what the patient wants. They really do.” (57)

**Barriers and facilitators of ACP**

The current literature recognises that ACP uptake is increased when raised by an oncologist (58) however there are some barriers with engaging oncologists in the process. These include a lack of communication about prognosis between oncology healthcare professionals and their patients (47), no clear definition of whose responsibility it is to complete advance care planning (48), perceived lack of time from clinicians (47), oncologists perceptions of autonomy and the role of the patient in
decision making (57), resource constraints (57), lack of knowledge and for some oncologists a perception that ACP has become about “political correctness... and is just a process to keep administrative happy.” (57)

For people with cancer, some of the barriers to participating in ACP have been identified as lack of knowledge about ACP, being too busy to complete the forms with competing priorities, finding the process too confronting and skepticism that their documentation would be located and then actualized. (52, 53, 55, 56)

Resoundingly, considering ACP within the context of a patient and family centered approach and involving support people in conversations were seen to positively impact uptake and participation. (48, 49, 52) The literature provides clear evidence that the majority of people with cancer are more likely to participate in ACP if their support person is involved. (48, 49, 52) In conjunction with this, taking time and introducing ACP over multiple interactions and being flexible with the approach were all highly valued by people with cancer (54).

There has also been success in improving uptake of ACP using particular communication models. One study exploring the use of the vignette technique as a potential tool for facilitating ACP discussions demonstrated an increased knowledge of ACP, awareness of patient’s values and preferences and greater confidence of patients and their support people in discussing their views with healthcare professionals. (54) Another study using trained nurses and allied health professionals with the ‘Respecting Patient Choices’ model were able to increase the documentation of Advance Care Directives, appointment of a substitute decision-maker, preferred place of death and wishes regarding specific interventions like CPR. (48) It also demonstrated increased communication between patients, oncologists and family members 6 weeks post ACP discussions. (48)

**Discussion**

The role of ACP as a key component of optimal care in the oncology population is increasingly acknowledged in policy documents and by peak body oncology organisations in Australia. (18-25) It appears that this view is shared by both oncology healthcare professionals, people with cancer and their support people. (53-57) This is consistent with many international systematic reviews which have also shown the acceptance and benefits of advance care planning within the oncology
From an international perspective, the results found in this review are comparable to many international studies which have also highlighted the barriers of ACP relating to the patient, provider and healthcare system. (35) These have been documented as including patient anxiety, insufficient physician training and time, the impact of the healthcare provider’s beliefs and the difficulties with locating information in health records. (43) In addition to this, many personal factors, factors related to patient circumstances, patient comprehension and awareness have been acknowledged internationally as key barriers to consider in ACP for people with cancer. (35)

Similarly to findings from this review, studies in ACP at an international level have also concluded that ACP needs to be an ongoing conversation with shared decision making that includes not only the patient but their support person. (35) The literature on ACP makes it clear that the majority of people with cancer consider the welfare of their support people when deciding whether or not to participate in ACP and if they choose to engage in ACP they generally approach it as a shared experience with their support people. (33, 59-61)

There is limited exploration about the timing of ACP conversations or the role of advance care planning in consent for people with cancer in the Australia literature. The majority of studies conceptualized advance care planning and/or advance care directive implementation within an end-of-life care context. In the one study where it was discussed, participants felt end-of-life conversations should be introduced when their disease became incurable. (49) The international literature also suggests that all stakeholders are reluctant to initiate ACP conversations early and prefer to delay ACP until the issue is raised or later in the illness trajectory. (62-64) There has been limited research internationally about the introduction of ACP in the oncology population at cancer diagnosis however, a survey of nurses in America showed that they were advocating for this to occur. (65)

Across international literature, it is explicitly and implicitly expressed that doctors feel they are best placed to determine when people with cancer are ready for ACP. (58-61, 64, 66, 67) This scenario signifies that doctors effectively ‘control’ ACP in oncology and references to the power of doctors and the degree of control that they have over the patients and other healthcare professionals is apparent in international ACP literature. In one study, nurses felt that they needed more autonomy to initiate ACP discussions “without doctors” permission. (65) In another study, patients and their support people explicitly stated that oncologist discomfort in discussing and initiating EOL conversations was a barrier to participating in discussions. (64) The most appropriate model for
delivering ACP and whose responsibility it is, needs to be further explored amongst the Australian oncology population.

The barriers and facilitators described in ACP in the oncology setting are similar to those found in aged care, general medicine and other populations. (68) Both the Australian and international literature suggest that there is a need for a systems based approach and increased education amongst both healthcare professionals and people with cancer and their families to increase ACP uptake.

Further research is needed to thoroughly explore the knowledge, perspectives and experiences for people with cancer and their support people in regards to ACP. ACP needs to be defined both within consent and end-of-life care contexts. The current body of Australian literature identifies a number of important themes regarding ACP in the oncology population however, these ideas have been generated from a cohort of participants who are being treated in metropolitan areas and are not reflective of a national oncology population. Furthermore, qualitative research is needed to explore the knowledge, perspectives and experiences of oncology healthcare professionals concerning ACP. The current Australian literature in this area is limited to one study with small numbers and was centered around autonomy rather than the broader principles of ACP. This approach would provide a more meaningful understanding of the barriers and facilitators to ACP in the Australian oncology population.

**Conclusion**

ACP has rapidly become not just a recommendation but an expectation in oncology. The benefits of ACP for people with cancer, their families and the healthcare system have been well documented. In order to improve ACP participation in people with cancer, interventions should address both personal and healthcare professional factors at a system-wide level. Systems should promote an early and continual discussion of ACP and involve support people. Further Australian research is needed to examine the barriers and facilitators for healthcare professionals, people with cancer and their families at a national level.
References


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<tr>
<th>Reference</th>
<th>Country</th>
<th>Number participants</th>
<th>Type of participants</th>
<th>Method(s)</th>
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<td>147 patients from</td>
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<td>116 patients from</td>
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<td>Prospective, multi-site randomised control trial</td>
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<td>Australia</td>
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<td>Australia</td>
<td>85 patients and</td>
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<td>cancer and 6 family</td>
<td>chemo</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1- Study characteristics and thematic grouping of included studies.